MODEM

modelling outcome and cost impacts
of interventions for dementia

Advance Care Planning

Advance care planning involves people thinking and talking about how they would like to be cared for in the future. Anybody can develop an advance care plan. However people usually plan ahead because they have a condition, such as dementia, that means that they may not be able to make their own decisions or clearly communicate their wishes in the future. It is completely voluntary; people do not have to have a discussion or develop a written plan if they do not want to.

Key points from the research:

- advance care planning allows a person to have their wishes taken into account even in the advanced stages of their condition and at end of life when they are no longer able to make their own decisions
- it works best when there is a supportive discussion with a health or social care professional so that people understand their condition and care options. This can also help to make sure that written advance care plans are clear and easy for doctors and other care providers to understand
- advance care planning can help to reduce unnecessary emergency admissions to hospital and improve the quality of end of life care
- advance care planning may help to ensure better use of health and social care resources.

What is Advance Care Planning?

Advance care planning discussions are very personal and individual. They often take place with the support of others such as a general

practitioner (GP) or other health or social care professional, family members or the person's family carer.
In England, if people choose to make an advance care plan they can write their wishes down in:

- an advance statement, which can cover anything to do with future care such as the values that they want to guide their care, their thoughts on different treatment options or where they would like to be cared for. It can include all types of wishes, not just those about medical care.

- an advance decision, sometimes called an advance decision to refuse treatment (ADRT). This is a decision to refuse a specific type of medical treatment in the future if the person loses the ability to make his or her own decisions. It is usually legally binding.

If they wish to, a person can choose somebody else to make decisions on their behalf if they are unable to make them in the future. This is called a Lasting Power of Attorney (LPA) for health and welfare. Other countries have similar arrangements for people wanting to develop an advance care plan although the documents and processes involved may be called different things.

It is best if advance care planning is carried out with people with dementia before they lose the capacity to make their own decisions and express their wishes. However where this is not possible, an advance care plan is sometimes developed with a family carer to help make sure that care is given in the way that is in the best interests of the person with dementia and in a way that the carer believes the person with dementia would wish.

There is further information on advance care planning in the booklet: 'Planning for your future' published by the National Council for Palliative Care.

Why is Advance Care Planning important for people with dementia and their carers?

As their illness progresses, people with dementia are likely to find it increasingly difficult to communicate. Planning ahead allows them to share their views on future care and what is important. It can be reassuring for family carers to know that care is being given in the way that the person would want.

Advance care planning can also help to reduce avoidable emergency

hospital admissions and care that will not benefit a person at the end of their life. A supportive care approach (we call this palliative) to relieve discomfort and distress is usually appropriate for people with dementia in the late stages of their life. However, this type of approach is not always taken. Instead, people with advanced dementia often experience emergency hospital admissions and distressing medical treatments despite the likelihood that this will not improve or maintain their quality of life. Advance care planning can help people to die in the place they choose, which for most people is their own home or care home.

Does Advance Care Planning work?

It is difficult to assess how well advance care planning works because there is no single way of doing it and the experience of advance care planning varies from person to person, including how and when it takes place and which professionals are involved. There are also many different possible benefits that can come from having these discussions, some of which are hard to measure. As well as fewer hospital admissions, benefits can also include helping people to understand their health condition better and improved communication with health and social care professionals. A recent review of research on advance care planning (for people with a range of different health conditions, not just dementia), found that it can improve the quality of end of life care particularly when there has been a discussion supported by a health or social care professional rather than just completing documents. (1)

A number of studies have specifically looked at advance care planning for people with dementia and also identified positive benefits. For example, a large study in the United States found that people with severe dementia, living at home, who had an advance decision to limit treatment in certain circumstances, (called a treatment-limiting advance directive) were significantly less likely to die in hospital than those without an advance decision. Two other studies, one in Australia and one in Canada, found that people in nursing homes using the 'Let Me Decide' advance care planning programme spent less time in hospital and had fewer emergency admissions.

Giving people with dementia food and fluids artificially (this is called 'tube' feeding ') in their last weeks of life is not usually thought to be a good idea. It can be very distressing for people with dementia and their families and often requires hospital admission. It has also been shown that there are no clear benefits to 'tube' feeding in terms of the

length or quality of life of the person or in improving their nutrition (2) A number of studies have found that people with dementia in nursing homes (3,4,5,6) and in hospital (2) who have an advance care plan are less likely to be 'tube-fed' towards the end of their life.

Another study in the United States found that family carers were more satisfied with the end of life care given to their relative when staff at the nursing home spent time discussing their relative's advance care planning with them. (7,8)

Is Advance Care Planning cost effective?

Advance care planning may help to ensure better use of health and social care resources. There are no studies so far that have looked at the overall balance between the different costs and benefits of advance care planning. (9) However, there are a number of studies that show that advance care planning can help to save hospital costs. (9) It is likely that this is by reducing time spent in hospital and unwanted treatments. Two of these studies involve people with dementia. (10,11)

Because community-based care is generally thought to be less costly than hospital care, and because people with dementia are also more likely to get the type of care they want, advance care planning is widely thought to offer good value for money (be cost-effective).

What people say about Advance Care Planning?

Two people talk on the Dementia Diaries website about why planning for the future is important to them:

Ann Scott talks about why Advance Care Planning is important for her:

http://dementiadiaries.org/entry/4810/advanced-care-planning-is-very-important-the-burden-of-my-future-is-not-put-on-my-family

Anne MacDonald talks about choosing to have a power of attorney in place before a crisis situation:

http://dementiadiaries.org/entry/3112/so-important-to-have-a-power-of-attorney-in-place-before-a-crisis-situation

Further information

If you would like find out more about planning ahead and how to develop an advance care plan there is further information on the following websites:

NHS Choices:
http://www.nhs.uk/Planners/end-of-life-care/Pages/why-plan-ahead.aspx

Alzheimers' Society
https://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=143

Dying Matters
http://www.dyingmatters.org/page/planning-your-future-care

Marie Curie
https://www.mariecurie.org.uk/help/terminal-illness/planning-ahead/care-planning

It may also be helpful to read the booklet 'Planning for your future' published by the National Council for Palliative Care:

Resources

Further information on advanced care planning for health and social care professionals:

Social Care Institute for Excellence: dementia gateway
https://www.scie.org.uk/dementia/supporting-people-with-dementia/decisions/advance-care-planning.asp

Advanced Care planning: a guide for health and social care staff
http://www.ncpc.org.uk/sites/default/files/AdvanceCarePlanning.pdf

Organisations

Find out more about organisations that have information or offer support to people with dementia and their families.

Author: Josie Dixon
Edited by: Helen Hayes and Adelina Comas-Herrera with support from the MODEM user and care group.
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The Evidence Table Key

Does it work?

✓	Worked well
✓=	Worked well in some studies and made no difference in others
✓=X	Mixed results it worked well in some studies, made no difference in others and some found negative impacts
=	Made no difference
=X	Made no difference in some studies and others found negative impacts
X	Negative impact

Is it cost effective?

✓	It was cost effective
✓X	It was found to be cost effective in some studies and not in others
X	It was not cost effective

What is the strength of evidence?

This rating will depend on a range of factors such as the type of research for example if it was a Randomised Controlled Trial (RCT) and the number of people who participated in the study.

✓✓✓	High Quality
✓✓	Moderate quality
✓	Low quality

Overall Findings for ACP

Does it work for the person with Dementia?	Does it work for family and carers?	Is it cost-effective?	Strength of evidence	Implemented in the UK?
Hospitalisation ✓ Place of death ✓ Carer Satisfaction ✓ Tube Feeding ✓		Likely to be cost effective ✓	✓✓	✓

Findings of individual studies

Study	Does it work for the person with dementia?	Does it work for family and carers?	Is it cost-effective?	Strength of evidence
Garden et al., 2016 Before-after, no control 283 nursing home residents, 250 staff UK	Hospital admissions ✓ Place of death ✓ Staff confidence ✓ Carer satisfaction ✓			✓
Hilgeman et al., 2014 Randomised controlled trial 18 people with mild dementia and carer US	Depression ✓X Quality of life ✓X Coping ✓ Decisional conflict ✓ Mobility ✓ Anxiety, Meaning, Social engagement, Emotional support, Anticipated support, Self-care, Usual activities, Pain/ discomfort X	Depression ✓ Quality of life ✓ Self-care ✓ Usual activities ✓ Anxiety ✓X Social engagement, Mobility, Pain/ discomfort X		✓

Findings of individual studies (continued)

Nicholas et al., 2014 Retrospective cohort 3,876 people age 65+ US	Reduced hospital death ✓ Reduced Intensive Care Unit (ICU) use ✓ Fewer life sustaining treatments X		Reduced Medicare spending in last 6 months ✓	✓✓✓
Vandervoort et al., 2014 Retrospective cohort 101 nursing home residents Belgium	Emotional distress ✓ Physical distress, Dying symptoms, well-being X			✓✓✓
Livingston et al., 2013 Before and after, no control 120-bed nursing home UK	Place of death ✓ Hospital days in last 3 months X Carer satisfaction ✓			✓✓
Keily et al., 2012 Prospective cohort 323 nursing home residents US	Carer satisfaction ✓			✓✓
Vandervoort et al., 2012 Retrospective cohort 764 nursing home residents Belgium	Place of death, Quality of life, Perceived 'mildness' of death and Symptoms X			✓✓✓

Findings of individual studies (continued)

Engel et al., 2006 Prospective cohort 148 nursing home residents US	Carer satisfaction ✓X			✓✓
Caplan et al., 2006 Non-randomised controlled trial Three hospitals and 34 surrounding nursing homes. US	Emergency ambulance calls ✓ Hospital days ✓ Hospital admission ✓			✓✓
Morrison et al., 2005 Cluster randomised controlled trial 139 nursing home residents US	Concordance ✓			✓
Volicer et al., 2003 Cross sectional, convenience sample 156 recently bereaved carers US	Hospital days ✓ Place of death ✓ Comfort in dying X			✓
Mitchell, 2003a Cross-sectional 186,835 nursing home residents US	'Tube' feeding ✓			✓✓✓
Mitchell 2003b Cross-sectional 1,057 nursing homes US	'Tube' feeding ✓			✓✓✓
Meier et al. 2001 Prospective cohort 99 hospital patients and their carers US	'Tube' feeding ✓			✓✓✓

Findings of individual studies (continued)

Ahronheim et al., 2001 Cross-sectional 57,029 nursing home residents US	'Tube' feeding ✓			✓✓✓
Gessert et al., 2000 Cross-sectional 4997 nursing home residents US	'Tube' feeding ✓			✓✓✓
Molloy et al., 2000 Cluster randomised controlled trial 1292 nursing home residents Canada	Hospital days ✓ Hospitalisation ✓ Satisfaction X		Hospital costs ✓ All healthcare + intervention costs ✓	✓✓✓

Find out more about the Modem Dementia Evidence Toolkit:
http://toolkit.modem-dementia.org.uk

If you have any questions please contact us: pssru.modem@lse.ac.uk

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